Volume 5
Issue 1
October 1998

H.A.L.O. Reports

A Publication from the Help A Little One Foundation

H A L O
HELP A LITTLE ONE

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Founder's message

Sarah's smile is a gift

Dear Friends,

One of Webster's definitions of a smile (n.) is: a change of facial expression in which the eyes brighten and the lips curve slightly upward, especially in expression of amusement, pleasure, approval, or sometimes scorn.

When your toddler wakes you early on the weekend, can you not smile back into those dancing eyes? When your teenager wins the lead in the play, is it possible not to be infected by her exuberance? The shyest smile, the greatest grin, even the sassiest smirk are moments not to be taken for granted. A smile is a gift.

Until recently, we had not seen our younger daughter Sarah smile for the better part of seven years, ever since a virus devastated her neurological function and left her with little response to the outside world. Oh yes, a grimace resembling a smile might occasionally move across her face, but it has been for no ascertainable reason.

On the other hand, Sarah has clearly and steadily expressed her dissatisfaction by crying when she has been cold or tired or unhappy. It has happened almost every morning for the past year, since she has been strapped to a device and helped to stand vertically for 30 to 60 minutes in order to improve her bones and correct hip dislocation.

So you might appreciate our excitement when Sarah has seemed to direct some authentic smiles our way. Gayle has witnessed Sarah's smile lately, in response to her familiar voice during her visits at New England Pediatric Care in North Billerica, Massachusetts. Sarah has actually giggled when Gayle has bounced her in play on her bed, and expressed real enjoyment when Gayle moved her arms to the beat of music.

We are not foolish enough to believe that there will be a spontaneous regeneration of dead brain matter. But this new responsiveness — some even believe Sarah responds to a song with her name in it — is a gift. Sarah seems to take pleasure in these small things. We take great pleasure in seeing her smile.

Our message to you as the holiday season approaches is to capture all your family's smiles in your heart and return the favor often to all your friends and family.

Sarah has been ill for seven years. H.A.L.O. has thrived the past five years because of her inspiration. We continue to seek your financial support, while we look for a new direction to evoke smiles from more children like Sarah.

Sincerely yours,

Alan Pinshaw

A Foundation for Neurologically Impaired Children

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The Drew family looks out for all their boys

Nine-year-old Ray Drew brings out the best in his family.

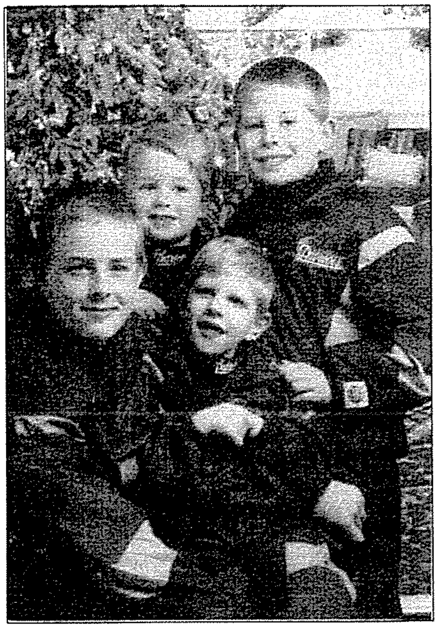
Just recently, Dennison, 6, tried to make sure that Ray would be included in golfing lessons proposed for the boys. When Susan and Jim Drew, Jr., gently reminded Dennison that Ray can't stand up, he countered that one parent could hold him by the waist, and he would guide Ray's arms to swing the club. He didn't want Ray to miss out on the experience.

Almost two years ago the Drews made the difficult decision to place Ray in a pediatric nursing facility, where he could get around the clock attention for his neurological, orthopedic, visual and hearing impairments.

Brother Wes, 10, exacted a promise from his parents that Ray would come home to Hingham, Massachusetts, for every birthday and holiday and more. Except for New Years Eve, when it's too cold for Ray to attend First Night activities, Ray does join the family.

From birth to eight years Ray lived at home and attended the South Shore Education Collaborative. At the school's "Extra Special Olympics" the brothers became friendly with the children of a teacher.. Brother Jimmy, now 13, explained to his parents that Ray was a great brother because he provided the opportunity to meet friends they might not have found on their own.

"I always do marvel that the siblings are so interested in Ray," said dad Jim. "The boys are compassionate and really caring individuals who wholly embrace the time they have to spend with their brother. They seem to understand that taking care of him is a lot of work, so when Ray is here they offer to get things for us, help us out. It is amazing to me."



The Drew boys last Christmas: Ray is front and center; from left: Jim, Dennison and Wes.

Sue Drew says she and her husband have always had a positive attitude. "If something happens, and it might appear bad, we look what good can come out of it."

Every time Ray comes home, it's "party time." The kids like to play with Ray, touching him, putting soft toys in his hands, rubbing his head. Sometimes when Ray is lying down, they will blow puffs of breath on his tummy, making him laugh and laugh and laugh, says Sue.

Developmentally, Ray functions at the level of a six-month-old baby. He loves to be cuddled, and since he's just 48 pounds, Sue says he tends to be passed from one set of arms to another as the maternal and paternal grandparents stop by and, occasionally, Ray's retired health care worker Evelyn and her husband Al, also.

Typically, Ray will arrive home in his wheelchair via a special van. It takes about an hour to and from New England Pediatric Care in North Billerica, MA. Five or six years ago, the Drews added a ramp for his wheelchair, and a wing with a first floor bedroom filled with things for Ray. A baby monitor transmits sounds to Sue and Jim's room above, although Mom says she's aware of Ray's every nuance.

Staying overnight is more relaxing for Ray and gives the family more time together, especially if the other boys have sports. Sue said Ray isn't happy to get into a car and sit at a field when he's just had a long ride home in the van."

With four children, life has always been pretty chaotic in the Drew household. The family has shared dinner and privacy with a home health aide ever since Ray was three. Since mealtime with Ray could take well over an hour, and a lengthy bath evoked his happiest responses, the aide's support released Sue to devote some of her time to the other children but also left her feeling she didn't provide Ray with all the support he needed.

"Slowly, I began to realize there were a lot of things that families take for granted that were missing for our other boys, but weren't fun for Ray," said Sue. "For instance , a walk on the beach after supper, or ice cream on a summer evening."

"Ray likes and needs his routine. If he isn't in bed by 7:15 he will cry and be unhappy. So I would stay with Ray. He is unaware of the things he is missing, but I realized I was missing out on times I could never replace. I was beginning to see that with a non-family member at the dinner table every night, no matter how loved and respected she is, my pre-teen wasn't able to speak freely about his concerns."

Ray's move to residential care

(Continued on back page)

Cedarcrest volunteers are "Peerless" in many ways

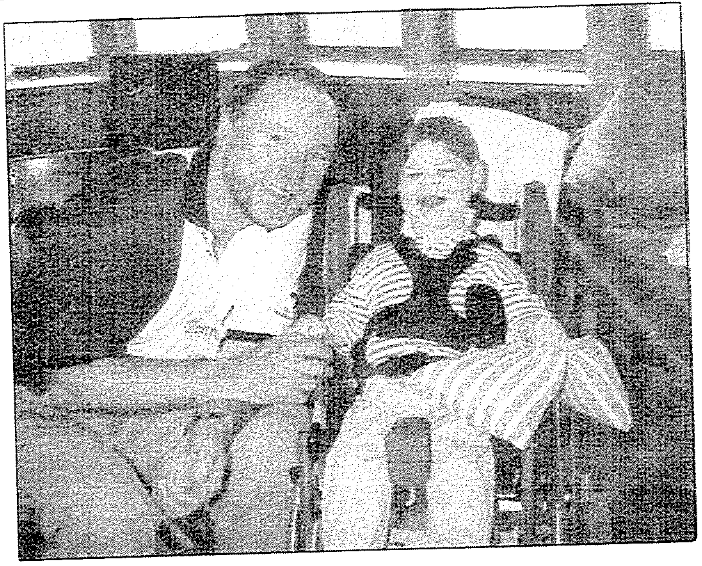
Employees at Peerless Insurance Company in Keene, NH really look forward to lunch. Oddly enough, two dozen of them don't eat.

Twenty-four volunteers take turns skipping lunch to volunteer at Cedarcrest, located just across the street. Cedarcrest is a home, school and medical support facility that provides specialized medical, therapeutic and educational serves to children, birth to age 16. All the children are medically fragile and/or have complex medical needs. Typically they function below age level, usually at the level of a six or nine month old baby.

The volunteers are matched to two or three children, so a familiar face will always be there if a volunteer changes jobs or is otherwise unavailable. Teams of four or five volunteers report on the same day each week.

Most of the children have been fed by the time the Peerless volunteers arrive, so the partners cuddle, read a story, massage their feet or put lotion on their hands.

"The volunteers are tremendously valuable because they give the children their undivided attention during the staff lunch period," said Elaine Giacomo, director of Development at Cedarcrest. "We know we can count on them to be there, rain or shine."



John Clifford, Regional Vice President at Peerless Insurance Company, and his lunchtime buddy, Garret.

John Clifford, Peerless Regional Vice President for New Hampshire and Vermont, a volunteer and one of the organizers of the project says: "We get a lot more out of it than we give."

"We get such an emotional lift out of it, we get so fully involved. . . It puts life in perspective very quickly for us."

Peerless's regional office had been donating money to Cedarcrest at holiday time for years — raising nearly $1,000 last year through bake sales, raffles and other efforts. But when Leeann Putska approached John about providing more personal ways for employees to "make a difference" Cedarcrest did not immediately come to mind.

"People often have a sense that our population is so medically fragile that there isn't anything they would be capable of doing," said Lori Bartashevich, volunteer coordinator at Cedarcrest. "It's not an easy thing to do. People can be squeamish."

After employees said they did not want to steal time from their families, lunch time became the target. Cedarcrest was so convenient inquiries were made.

Lori paid a visit to Peerless where she met 28 potential volunteers, showed them the Cedarcrest video, then offered them a choice of tour schedules. As a result, 24 employees decided to volunteer. The company then allowed them extended lunch periods to attend Lori's training sessions on how to work with the children.

"I tried to make our kids real, not just a medical diagnosis with a trach(eostomy), oxygen tank or seizures. I described the kids as the one with the biggest brown eyes, the greatest smile.

"I kept breaking it down into do-able tasks that address the same basic human needs they fill with their own kids all the time."

The response was wonderful.

"These are extremely caring people" said Elaine Giacomo. "They are providing extra attention to our children."

"We had been trying to get one little boy to be more mobile by using a walker. "Tim" loves a special musical toy, so his volunteer plays the music as an incentive for him to move a few more feet. One day when the music box was broken, a volunteer sang to "Tim" instead.

Parents are also enthusiastic. After meeting one of her daughter's lunchtime buddies, one mother who is unable to visit every day told Lori she feels great peace of mind when she looks up at the clock at noon, and knows someone special is spending time with her daughter.

Additional Peerless volunteers — from senior management through clerical workers — have joined the program or replaced members of the original group. John Clifford does not see interest dwindling. On the contrary, fundraising continues at the insurance company. John said the regional office goal is to raise $1,700 this year to provide a hydraulic table.

Partners for Youth offers support to higher functioning teens

Partners™ For Youth With Disabilities is a non-profit organization providing educational and social role modeling to help youths with disabilities ages 6-22 to reach their full potential for personal development.

Directed by Regina Snowden and a staff of four full-time and five part-time counselors and outreach workers, offer five programs and currently serves about 300 youth in the Greater Boston area. Participants can live with their parents or in residential programs. Outreach specialist Joni Mullane described the services as:

Mentoring: Partners matches youth and adults with similar disabilities in one-to-one relationships to provide role models and to inspire, develop and provide opportunities to increase self esteem and motivation for youth with disabilities.

Peer Leadership Training Program: Develops leadership and job readiness skills through involvement in after school community service. A weekend retreat introduces team building, panel discussions on topics such as disability awareness, conflict resolution, effective communication, advocacy and independent living. Peer Leaders volunteer in the other programs described here.

Youth In Preparation for Independence (YIPI): Youth with disabilities ages 11-19 share important concerns and coping strategies about day to day issues at weekly networking sessions.

Young Entrepreneurs Project (YEP): A fun workshop for young adults ages 14-26.to develop job readiness skills. Youth learn business basics such as writing a memo, opening and using a bank account, designing business cards, flyers and posters, setting prices and writing a business plan. Participants also take part in exercises which teach initiative, honesty and persistence. Adult volunteers with or without a disability serve as mentors.

Making Healthy Connections is a short term workshop informing youth ages 15-21 about medical issues. Topics include understanding your medical needs, relationships and sexuality, independent living, health, fitness and nutrition, sports and recreation, talking with health care providers, rights to privacy, adaptive driving and transitioning to adulthood. This pilot program is being offered in collaboration with Shriners Hospital for Children in Springfield and Boston Children's Hospital.

For more information on participating, either as an adult or youth, contact Partners For Youth With Disabilities at the Massachusetts Office on Disability, One Ashburton Place, Room 1305, Boston MA 02108 Telephone(617) 727-7440 or (800)322-2020 Voice and TDD.

National video promotes access in schools

BOSTON, MA —Two Massachusetts school districts will be featured in an 18-minute video which will be distributed nationally to help public school districts understand their responsibilities under the Americans with Disabilities Act (ADA) and other federal disability laws.

The goal of the project is to promote the inclusion and integration of people with disabilities in their communities.

Students, parents and employees with a disability from Framingham and Westport will be featured in the video. Participation in the context of an after-school activity and a community activity will also be included.

The video will be distributed at no cost through the ten national ADA centers, State Departments of Education and federal Department of Education regional offices. This project was funded by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education.

Adaptive Environments Center provides a Schools Hotline to help people with disabilities learn about their rights. Call 1 800-893-1225 ext. 28 voice or TTY. Adaptive Environments is located at 374 Congress Street, Suite 301, Boston, MA 02210.

Ray Drew's family is there for each other

(Continued from page2)

fulfilled everyone's needs. Sue said she feels assured Ray gets attention 100 percent of the time he needs it, and the family is devoted to Ray and thoroughly enjoys him when they visit him, and when he comes home.

"We consider Ray our special little guy. We tell all the kids they are special in their own way. Ray is special because he is different," said Sue.

"Ray has taught all of us never to take anything for granted. With our first two children we took it for granted they would roll over, reach out, hold a bottle, crawl and walk. They were milestones, but expected. When Ray didn't accomplish those milestones, and then Dennison came along, we appreciated those things much more."

Jim Drew adds one more comment: "When we first learned of Ray's problems, counselors delivered time and time again the disheartening news that 98% of all couples in our situation divorce over these issues.

"Sue and I focused on getting the best out of this. In all honesty it strengthened our marriage and made it better. We know more about each other now than we ever did. I want other people to know that marriages can survive such a strain. We are living proof."